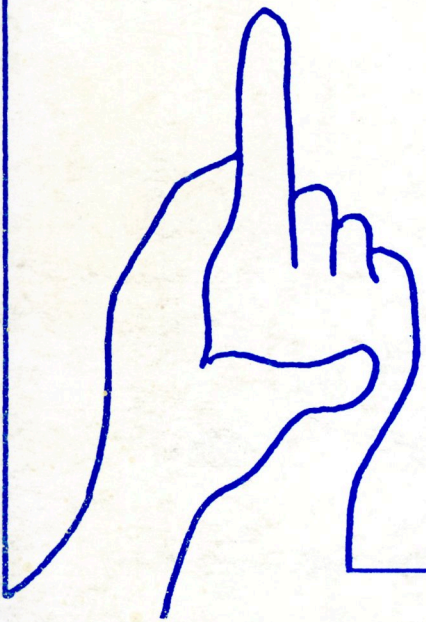
Movement Disturbance: A Clue to Hidden Competencies in Persons Diagnosed with Autism and Other Developmental Disabilities

by

David A. Hill and Martha R. Leary



"Movin' On" Beyond Facilitated Communication
Prof. Anne M. Donnellan, Series Editor

WHAT IS AUTISM?

"...autism is not a disease but a behavioral syndrome." Rapin (1987)

"...autism is the 'way people are' rather than a 'thing people have.' It is a reason for investigation, not an explanation in itself." McKinlay (1989)

"...organic disturbance and autistic syndromes of behavior go hand in glove with each other, and they are mutually inclusive, not mutually exclusive." Darby and Clark (1992).

"The consensus now is that autism is a behaviorally defined syndrome; it can be caused by one or more types of brain pathology that, in turn, can have one or more causes." Ritvo and Ritvo (1992)

"When you look in their eyes, you know..." Lehr (1992).

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Foreword

The widespread introduction of Facilitated Communications to people diagnosed with autism and other developmental disabilities in the early nineteen nineties brought the notion of accommodations, aids to expression long used for people with neurological disorders, to a population that few people had imagined capable of taking advantage of it: individuals with developmental disablities and chiefly nonverbal people diagnosed with autism, Down syndrome, Rett's syndrome, and many related impairments. But take advantage they did! and in so doing demonstrated many previously hidden competencies that astonished almost everyone, often dividing observers into those who believed what they saw, and those who did not.

Of course, there is much yet to study and learn about facilitated communications and other accommodations for people with significant cmmunication challenges. Nonetheless, those of us who have faith in the personalities who express themselves with newly disclosed literacy have had to abandon much of what we thought we knew about disabilities, and look for alternative explanations for behaviors that had previously been explained away as characteristics of retardation—whatever that might be—or some other self–defining insufficiency.

We believe authors of this monograph, whose work has focused on issues of autism, have begun to tease out answers to two important questions; why are facilitated communications possible? and what are some of the underlying impairments that gives rise to autistic and some other symptoms of developmental disability? As editors of the ***'Movin' On"*** **Beyond Facilitated Communication** series of books and booklets we are proud to be publishing this truly important manuscript for communicators, parents, teachers and other professionals who are unlikely to have easy access to scientific literature yet want to keep abreast of developments in the field.

Prepared for us by David Hill and Martha Leary from a text they have written for professional readers, this monograph still has the format of a scientific paper, with all the most important references from their original included in the alphabetized bibliography, and cited in the text in professional style, that is with principal authors and date of publication in parentheses, in the sentence that refers to the original work. Thus (Bruner, 1987) indicates a quote from the forward Dr. Jerome Bruner wrote for an English translation of a book by the Russian psychologist A.R. Luria called

The Mind of a Mnemonist—a wonderfully written book about an extraordinary man who quite literally could not forget anything that he had seen or heard! Almost all of 60 references in the bibliography and list of suggested readings are likely to be available in a college or university library. We hope readers will have an opportunity to review at least a sampling of the scholarly works the authors drew upon in their search for support of their exciting hypotheses.

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Introduction

We are speech language pathologists who work with people with autism. In March, 1991 we sat in an office in Syracuse, New York and watched a videotape of a young woman typing out her conversation while a facilitator supported her hand and ducked from her attempts to bite and scratch while typing. Later that day in an elementary school, we saw six and seven year old children with autism typing with facilitation while falling off chairs, lying on the floor and running from the room. We were convinced that these children showed the same symptoms as the children we knew back home. However, unlike the children we knew who struggled to point to a symbol, make a sign or speak a sentence, these children were engaging in conversations with other students, complaining about their school work and writing poems.

Our task after that initial introduction to facilitated communicating was to try to view autism from a different perspective. This new perspective included the notion that some individuals diagnosed with autism may be unable to let us know that they can think, listen, understand and feel because they are not able to organize, control and move their bodies at will. Dr. Douglas Biklen, in his article in the *Harvard Educational Review*, August, 1990, wrote that a condition called apraxia was preventing these individuals from expressing themselves adequately. Apraxia was generally defined as a movement disturbance.

The literature review reported in this booklet was our vehicle for viewing autism from a different perspective. In addition to the articles mentioned here, we read literature in other fields to try to understand how a point of view may affect every aspect of observation and study. During the project we tried to remain open to ideas and data that we may have previously put aside as irrelevant. We placed particular emphasis on reading first hand accounts written by or about individuals who had the ability to share their insights on how a movement disturbance affected every day life. Through these readings, our understanding of the nature and variability of movement disturbances came to include the large movements of the body (e.g. as in walking), the more subtle, but observable movements of eye gaze, facial expression and speech, as well as internal processes of perception, thought and emotions.

As clinicians, our goal was a practical one rather than an academic exercise. We set out to understand more about individuals with severe communication disorders but for practical reasons confined our literature search to studies of

autism. A secondary effect of our research has been to call into question the notion that autism exists as a unique, definable condition. The most widely used diagnostic manual, *DSM–III–R* (American Psychiatric Association, 1987, p.34), notes, "The evidence suggests [that autism] is merely the most severe and prototypical form of the general category Pervasive Developmental Disorders." We have come to believe that even this broadening of the definition may be misleading. Instead we prefer in our clinical work to focus on each individual's cluster of symptoms, rather than trying to group those symptoms into named syndromes like autism or PDD. In fact we believe our study has implications for people with many more forms of disability than individuals diagnosed with autism, and would urge readers to consider our conclusions in the light of their own observations of persons in their care, regardless of current diagnoses. We hope that our account of the possible relationships between "autism" and movement disturbance is helpful to you in understanding someone you know, and that understanding leads to better communication.

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Toronto, Ontario

I

Neurological Research Relating Movement Disturbance and Autism

> **Explanation of any human condition is so bound to context, so complexly interpretive at so many levels, that it cannot be achieved by considering isolated segments of life in vitro, and it can never be, even at its best, brought to a final conclusion beyond the shadow of human doubt.**
>
> (Bruner, 1987)

Scientific research is an exercise in discovery from a certain perspective or "paradigm." Data are collected, analyzed and interpreted in order to support, clarify and enlarge that perspective, which is constantly altered by the addition of new information. Researchers gather information within the context of the paradigm and in the process, build a body of literature which moves with a certain predictability, in a certain direction. New research builds on previous research, examining similar issues from a similar perspective all within the same paradigm.

The accumulation of research data on autism has given practitioners information to use creatively in assisting individuals with autism to learn new skills and to participate more fully in their communities. The research has also created a paradigm for viewing autism which has been helpful in managing the information.

However, in the interest of exploration it is important to consider those pieces of information which fall outside of the prevailing paradigm.

This booklet explores some of those interesting pieces of research which don't quite fit, and attempts to view the symptoms of autism from a different perspective. Discussion of these issues with a young man who uses facilitated communication (FC) to communicate yielded the advice: **"keep trying to learn, but never expect to know."**

Descriptions of children with specific handicaps involving communication,

social relationships and productive activity have been reported in the medical literature for more than a century (e.g. Kahlbaum, 1874/1973, Earl, 1934). In 1943, Dr. Leo Kanner described a small group of children with similar behavioral disturbances and suggested that "autism" was a distinct clinical classification. The body of research which has emerged since that time has helped establish autism as a psychiatric and/or developmental disorder, has developed ways of measuring and assessing the behaviors of these individuals and has further stimulated research in autism within the context of several professional disciplines. It is sometimes difficult to remember that autism is not a disease (Rapin, 1987), but a list of symptoms which certain individuals share in common. McKinlay (1989) noted a neurologist's frustration with the notion that autism is "a thing people have," (p. 22). Instead, he refers to autism as a description of the "way people are" (p.22), cautioning that a diagnosis of autism should not be the end result of a neurological investigation, but rather a reason for further investigation. In this monograph we have used the term "with autism" meaning "showing symptoms that have been diagnosed as autism."

Understanding of the neurological basis for the symptoms of autism and the possible relationship with other neurological syndromes has been limited. Indeed, at one time the prevailing perspective was that the presence of central nervous system (CNS) dysfunction in an individual was a reason to rule out autism as the diagnosis (Darby & Clark, 1992). The current perspective that autism can be caused by a CNS dysfunction (Ritvo & Ritvo, 1992) has opened the door to investigation of symptoms from a neurological perspective—a development that we welcome.

The profile of behaviors that fit within the symptom complex of autism are generally and reliably agreed upon by clinicians (Rapin, 1987). Symptoms typically are grouped as in *DSM–III–R* into one of three general areas of impairment: reciprocal social interaction, verbal and nonverbal communication, and restricted repertoire of activities and interests (American Psychiatric Association, 1987). Because these symptoms are observed in individuals with autism, several assumptions have been made about the underlying nature of the disorder.

Individuals with autism have been judged to lack internal feelings and empathy for others, to not desire social interaction, to lack communicative intent, to lack comprehension of language and situations, and to engage in maladaptive behaviors for stimulation and pleasure.

Attempts to describe and quantify the degree of impairment in various skills through psychological and psychometric evaluation meet with much difficulty. Often individuals are untestable when formal, standardized tools are used. Nonexistent or inadequate responses then yield failing scores; and certain assumptions are made about the source of difficulty when performance is poor. When a developmental perspective is taken, an individual who is unable to demonstrate knowledge or comprehension is

deemed to lack the necessary cognitive prerequisites for performance. Yet all tools for evaluation require that some type of expressive movement be made in order to demonstrate competency (e.g. pointing, talking, or manipulating items).

If an individual for whatever reason is unable to demonstrate an attribute or ability, particularly when such ability has not been previously observed or measured, the tendency is to assume that the attribute or ability is not present. Augmentative communication systems made available to people whose disability follows demonstrated competence allow many of them to continue to express themselves adequately. Stephen Hawking the astronomer is an outstanding example. And, recently people identified with developmental disabilities which clearly were seen to have a motor impairment (see Nolan, 1987) have begun to be served as well. Prior to the advent of facilitated communications, however, there was little effort to explore competency in people whose paucity of expressive mechanisms was assumed to reflect limited capaciities, a double bind that is now being undone.

The following discussion of movement in autism has been prompted by our work in communication, the success of facilitated communication and recent research in the field. We have chosen to set aside the traditionally held view of autism, at least temporarily, in order to consider autism from a different perspective.

This different perspective views behavior in autism as a consequence of an underlying disturbance in expressive movement and its regulation.

In undertaking this work, we reviewed the symptoms and characteristics seen in well-established neurological syndromes affecting movement, reviewed the research on autism in relation to movement disturbances, had long discussions with our colleagues, examined our clinical experiences working with individuals with autism, and applied an instrument used for description of movement disorder to the autism literature reviewed, and to the *DSM–III–R* criteria for autism.

The Symptoms of Autism and Movement Disturbance

Several investigators have suggested an association between symptoms observed in autism and specific types of motor and movement disturbances. However, due to lack of agreement on the nature of the underlying problem, different perspectives of the investigators, and the inability of the difficulties identified to account adequately for the most severe and core characteristics seen in individuals with autism (i.e. social and communicative impairments), this area of research has not been central to investigations of autism (Golden, 1987; Ornitz, 1985).

Damasio and Maurer (1978) and Maurer and Damasio (1982) described movement disturbances in individuals with autism that appeared similar to the difficulties in initiation and execution of spontaneous movements typically seen in Parkinson's patients. These were defined as: akinesia, the absence of movement; bradykinesia, slowness in movement; and dyskinesia, difficulties in movement.

Other apparently nonfunctional repetitive behaviors or stereotypies that have been observed in persons diagnosed with autism include: body-rocking, head-banging, hitting or biting one's own body, skin-picking, scratching, teeth grinding, nose-picking, hair-pulling, eye- and anus-poking, non communicative and/or repetitive vocalizations, breath-holding, hyperventilation, and swallowing air and burping, all of which are symptoms of Stereotypy/Habit Disorder (APA, 1987, p.93); a co–occurrence that has been noted elsewhere in the literature (Realmuto & Main, 1982; Wing & Attwood, 1987). A strong clinical relationship between autism and Tourette syndrome has been documented by some researchers (Comings & Comings, 1991; Sverd, 1991). Again, *DSM–III–R* lists as symptoms of Tourette Disorder: vocal tics such as clicks, grunts, yelps, barks, screams, sniffs, coughs, or words–sometimes obscenities. Motor tics include blinking, tongue protusion, touching, squatting, knee bends, retracing steps and twirling.

Disturbances in motor planning (i.e. apraxia and dyspraxia) have been observed in individuals with autism (DeMyer et al., 1972; Jones & Prior, 1985), and more recently have been suspected as the underlying "problem with praxis" (Biklen, 1990, p. 301) that accounts for the reported success of facilitated communication with some individuals with autism (Biklen, 1992). Definitions of these terms vary through the literature, but operationally both apraxia and dyspraxia can be thought of as a problem carrying out a planned or desired behavior such as striking a key on a typewriter or forming a letter with a pen. In his first article on facilitated communication, Douglas Biklen (1990) identified the movement difficulties in autism as *apraxia*. In order to further define apraxia, we reviewed some of the literature on it (e.g. Ayres, 1979; Goodgold-Edwards & Cermak, 1990) and Rett syndrome where apraxia is said to play a role (e.g. Lindberg, 1991; Van Acker, 1991; Burd, Randall, Martsolf & Kerbeshian, 1991). We found that the term apraxia was used differently in each reference. Heilman and Ganzales Rothi (1983) observed that apraxia is often defined by what it is not, rather than by what it is. In practise, apraxia is often used as a generic term to describe a collection of symptoms related to difficulty with voluntary or planned movements. It may be the case that Biklen was using the term in this way as well.

More complex disturbances in movement, volition, overall behavior and speech similar to catatonic phenomena have also been observed in individuals with autism (Wing & Attwood, 1987; Realmuto & August, 1991). The catatonias, which should not be confused here with schizophrenia, are

a huge range of behavioral disturbances that incorporate all of the symptoms described above plus a wide variety of complex behaviors that may include a long, connected and detailed sequence of apparently willful acts. Many are listed in Table 1, below.

Disorders of Activity: general overactivity, outbursts, destructiveness, self-mutilation, stripping, negativisms. Abnormal facial movements: expressionless, flaccid or fixed expression abnormal eye movements Abnormal gait: including halting, slow , and stiff gaits	**Abnormal speech:** mutism, decreased speech, slow speech, delay in answering. Increased speech. outbursts of speech, swearing, abnormal volume and timbre. Unintelligible speech, vocalizing, lip movements	**Disorders of posture:** flexion of head, trunk or limbs Persistence of postures: peculiar postures. and extension postures Disorders of tone: rigidity, stiffness, resistance to passive movement Disorders of motor performance: decreased activity, motionlessness, decreased responsiveness, and difficulty initiating

Table 1. Characteristics of Catatonia: after Kalbaum, (1874/1973)

After establishing the range of movement disturbances that have been related to the syndrome labeled autism we investigated the neurological disorders that are well-substantiated by research to be also closely associated with the movement disturbances. We were particularly interested in the subjective experiences of people who had these movement disturbances, and reviewed a number of first hand accounts. During the literature review we collected information on the onset, course and nature of symptoms seen in each syndrome. The neurological syndromes we investigated included:

a) **Idiopathic Parkinsonism** (Hoehn & Yahr, 1967; Still, 1984; Marsden, 1984) as an example of a disorder involving akinesia, dyskinesia and bradykinesia;

b) **Tourette Syndrome** (Campbell et al., 1972; Shapiro, Shapiro, Brun & Sweet, 1978; Shapiro & Shapiro, 1982; Butler, 1984; Bauer & Shea, 1984; Robertson, Trimble & Lees, 1989; Golden, 1990; Sacks, 1992) as an example of stereotyped movement disorder;

c) **Catatonia** (Kahlbaum, 1874/1973; Bleuler, 1911/1950; Abrams & Taylor, 1976; Wing & Attwood, 1987; Lund, Mortimer, Rogers & McKenna, 1991; Realmuto & August, 1991) and Post-encephalitic Parkinsonism (Sacks, 1990) as examples of syndromes involving abnormalities in movement, volition, more complex overall behavior, and speech. (Again, the use of the term catatonia here is as defined. It does not refer to a type of schizophrenic withdrawal as it is often used in the psychiatric literature.)

This process of identifying symptoms and matching them to similar symptoms in autism, as reported in research literature and *DSM–III–R* (APA, 1987), was most useful in clarifying the nature and scope of possible symptoms involved in a neurological syndrome affecting movement.

When one thinks of a movement disturbance, certain familiar images may come to mind. For example, movement disturbances evident in older people with Parkinsonism can include a tremor, observable effort in moving, excessive slowness or difficulty standing up when seated in a soft chair. The physical and vocal tics of Tourette Syndrome are also well known examples of movement disturbance. but it is difficult to relate these images to the youthful spinning and twirling of children diagnosed as having autism. As well, the symptoms which define autism (i.e. impairments in social interaction, communication, and activities and interests) may seem difficult to explain as manifestations of a movement disturbance (Golden, 1987).

It is when one searches beyond the familiar observable images to read of the experiences of individuals diagnosed as having Post-encephalitic Parkinsonism, Catatonia and Tourette Syndrome that a picture strikingly similar to autism emerges of movement disturbance affecting relationships, communication and productivity.

More precisely, a movement disturbance may cause difficulties with the dynamics of movements as in starting; executing (e.g. speed, control, target, rate, rhythm, coordination); continuing; stopping; combining; or switching movements. The levels of complexity of movements disturbed may range from simple (e.g. head nodding, pointing, smiling) to those affecting all aspects of behavior and activity (e.g. completing tasks, having a conversation, controlling impulses). In addition, individuals with movement disturbances often report differences in perception or changes in attention, consciousness and emotion. Disorders of the basal ganglia which are involved in movement disturbance also affect social and emotional movement (Maurer, 1992). A type of "emotional dyskinesia" may create difficulties with the control of the movements which a person uses to express emotional states (e.g. talking, laughing, gesturing, showing attention). A lack of control over emotional movement may result in a failure to "connect" or communicate with another person (Maurer, 1992, 1993).

Because many of these effects are psychological as well as physiological the cumulative effect of disturbances in the dynamics and levels of complexity of movement and variables such as changes in internal mental processes cannot be understood by an observer who has no access to a subject's thoughts. Table 2, below lists some symptoms of movement disturbance that can affect communication and social ability.

Overlapping Symptoms of Movement Disturbance and Autism Which Affect Speech Communication and Interpersonal Relations

Facial Expression and Eye Gaze:
- grimace or rigidity for no apparent reason
- decreased use of facial exression
- lack of facial responsiveness or socially inappropriate facial expression
- eye gaze/ocular abnormalities
- looks out of corners of eyes
- avoids looking adult in the eye/lack of eye contact

Meaningful Gesture:
- dyskinesia, akinesia, bradykinesia
- gesture is absent, minimal or socially inappropriate in form
- echopraxia/hypermimesis
- lack of imitation

Voice:
- dysprosody/abnormal melody
- poor speech volume, modulation
- abnormal tone, rhythm, volume
- vocal tics, screaming

Speech:
- mutism
- use of jargon
- unintelligible speech
- echolalia
- lack of initiation
- verbal stereotypies, including repetition of words, phrases
- lack of imitation

Conversation:
- topic perseverations
- unconventional expression of intent
- interactional rituals
- lack of response to others

Table 2

As a part of our investigation, we compiled a list of symptoms commonly

found in the three neurological syndromes affecting movement. We compared these symptoms to those reported in the literature on autism. Our search was broad but not exhaustive. When we found sufficient references for a particular symptom, we moved on to the next symptom.

The overlap or co-occurrence of symptoms between autism and the neurological syndromes affecting movement was remarkable. Although the age of onset and the course of these syndromes were clearly different from autism, the descriptions of the symptoms were very familiar and characteristic of symptoms found in autism.

Differential diagnosis of autism from various syndromes affecting personality, intellectual expression and communication is often difficult (Cohen, Paul & Volkmar, 1987) because of the similarities and overlap in symptoms. It was therefore necessary to find a way to organize and account for the variety and range in complexity of symptoms that were found to overlap. We needed to determine whether or not the overlap of symptoms was sufficient to give consideration to viewing autism as a movement disturbance.

In structuring our review we found it helpful to use a checklist called the Modified Rogers Scale (Lund, Mortimer, Rogers & McKenna, 1991), which was developed as a method of determining the presence of movement disturbance in a variety of conditions and syndromes. It is based on the work of Daniel Rogers, a British neuropsychiatrist, and his colleagues.

In a groundbreaking book Rogers (1992) challenges psychiatry's established and conventional interpretations of movement disorder in arguments that parallel many of the points made in this monograph. Noting that early in the twentieth century psychological explanations for emotional and behavioural disturbance gained such influence that, "Psychiatry and neurology developed along separate lines with little cross-fertilisation of ideas between them, to the detriment of both" (p. 10). In consequence, "...motor symptoms now became completely dependent on psychic factors for their [presumed] origin" (p. 11), He observes that, "...motor disorders in mental handicap [i.e., developmental disability, (ed.)] were dealt with very simply. Abnormal movements in the mentally handicapped were often lumped together as 'self–stimulation' with no attempt to study their prevelance..." (p. 62). Rogers presents a strong case for a much greater attention to the implications of movement disturbance in the assessment of psychiatric and developmental disorders.

More specifically, the items on the Modified Rogers Scale reflect the symptoms of catatonia as it has been traditionally or classically defined, that is, abnormalities in movement, volition, overall behavior and speech (Lund, Mortimer, Rogers & McKenna, 1991). Although this scale is typically used to assess an individual person through observation, we used it to categorize the overlap of symptoms which we found between autism

and the three neurological syndromes which we investigated. The results of this categorization, with specific references to the autism literature and the *DSM–III–R* criteria for autism, are detailed in another paper by the authors (Leary & Hill, in prep.).

Symptoms of Autism Which Overlap with Movement Disturbances seen in Parkinsonism, Tourette Syndrome, and Catatonia.

In total, twenty-four of the thirty-six motor abnormalities of the Modified Rogers Scale were applicable to autism and our use of the scale. The other twelve were not included only because they are not referred to in the literature. Future research will determine if they are applicable to individuals with autism. Some broad categories of the Scale are used in the following tables to present the overlap of symptoms between autism and other disturbances of movement documented in our earlier work (Leary & Hill, 1993). Table 3, **Disturbances of Motor Function,** lists overlapping symptoms affecting posture, muscle tone, associated movements (i.e., natural movements of the body during actions), and extraneous movements (i.e. additional non-purposeful movements such as tics).

Disturbances of Motor Function (posture, muscle tone and associated movements, and extraneous, non-purposeful movements)
flexion dystonia: e.g. transient stretch and flex of the limbs and trunk of the body
odd hand and body postures
abnormalities in muscle tone
teeth grinding
grimace or rigidity for no apparent reason
facial expression and gesture absent or minimal or socially inappropriate in form
lack of eye contact: e.g. looks out of corners of eyes, avoids looking adult in the eye
involuntary motor tics: e.g. arm flapping
choreiform & athetoid movements: e.g. involuntary writhing or dance-like movements
dyskinesia: e.g. decrease in voluntary, spontaneous and associated movements
motor stereotypies: e.g. peculiar hand movements, rocking, spinning, dipping and swaying movements of the whole body
vocal and verbal tics: e.g. unusual vocalizations or combinations of sounds
loss of associated movements: e.g. lack of or unusual swinging of arms while walking

Table 3

Table 4, **Disturbances of Volitional Movement**, deals with behaviors such as walking and speaking which are performed for a purpose, and where disturbances affect the voluntary nature of these movements or the will to move.

Disturbances of Volitional Movements (purposeful behaviors such as walking and speaking)

slowness/feebleness of spontaneous movements
motor planning difficulties
repetitious spontaneous movements, e.g. ordering, lining-up, separating items into discrete numerical or spatial piles
obsessive-compulsive behaviors
exploring objects through smell, taste and/or touch
persistent patterns of body movements
self-injurious behavior
motor perseveration
repetitive mimicry of another's actions and/or behavior
gait disturbances, e.g. reduced associated movements such as arm swing, slow, shuffling walk, manneristic or bizarre walking pattern such as lunging, jumping or toe walking
speech/language disturbances, e.g. abnormal speech melody
poor speech volume control
abnormal speech rate and rhythm
decreased number of communicative initiations, mutism
unconventional expression of communicative intent, use of jargon
repetition of words and phrases, echolalia, perseverative speech: e.g. topics, questions, words

Table 4

Table 5, lists symptoms associated with **Disturbances of Overall Behavior** or levels of activity. Movements described here are marked by extremes of rate (e.g. no movement, extremely slow or extremely fast movement) and extremes of intensity (e.g. unwarranted aggressive or destructive behavior, or inexplicable lack of response to stimuli).

Disturbances of Overall Behavior or Activity (increased or decreased rate and/or intensity of behaviors and responses)

catatonic excitement: e.g. frenzy or marked overactivity, extreme response to minor environmental changes
aggressive behavior
hyperkinesis: e.g. constant movement
explosive or violent movement episodes: e.g. tantrums
aversion to affection or physical contact

catalepsy: e.g. persistent, strange postures, freezing during movement
bradykinesia: e.g. excessively slow execution of movement
mutism: e.g. no use of speech or use of speech only rarely while under stress
no or impaired imitation
lack of response: e.g. when name is called or to a sudden sound
lack of initiation: e.g. waits for instructions before moving
catatonic stupor: e.g. stationary states accompanied by an intensification of attention as in a trance
negativism: e.g. does the opposite of actions requested
indifference to physical contact
ritualistic, repetitive actions and talk
follows routines in a repetitive way

Table 5

In addition to the observable movement abnormalities described above, a number of associated phenomena present in the neurological syndromes are also reported in the autism research literature, and as *DSM–III–R* criteria. These included:

a) presence of seizure disorders;
b) abnormal EEG, ABR, CT scan, and MRI findings;
c) presence of "soft" neurological signs; and
d) manifestation of "organic" dysfunction;
e) perceptual disturbances;
f) arousal and attention difficulties;
g) emotional lability: e.g. easily precipitated emotional displays;
h) arithromania: i.e. compulsion for numbers, counting and computing.

Implications of a possible movement disturbance for individuals diagnosed with autism

Before discussing how autism and syndromes that include movement disturbance may be similar, it is important to note some of the major differences. Unlike Parkinsonism, Tourette Syndrome and Catatonia, autism is usually present from birth or very early in childhood. The acquisition of skills in communicating, interacting, learning and attention are shaped by the presence of difficulties during this crucial time for development. As a result of these early difficulties the opportunities and experiences of the child with autism are substantially different from other children. People interact with the child often feeling that the child does not really enjoy the interaction. Education is attempted with a great deal of effort, along a narrow range of activities and topics, with minimal observable results. Speech language therapy may be effective in teaching the child to ask for basic needs, but falters when more conversational, interpersonal language is attempted. We can only assume that the impact

of these experiences on the child with autism would affect the development of his self esteem and his expectations for himself (Haskew & Donnellan, 1993). In contrast, the individual who has experienced a period of typical development before the onset of a movement disturbance, knows something of his abilities and his value in the eyes of others. The methods of coping with difficulties will likely reflect a previous history of competence. The child with autism may have no memory of competence on which to draw, but a long history of "incompetence" which affects opportunities, expectations and interactions on a daily basis.

The similarity between autism and neurological disorders affecting movement (i.e. Parkinsonism, Tourette Syndrome and catatonia) lies in the large number of symptoms they have in common (see Tables 3,4 & 5) But the symptoms found in the literature on autism cover a wide range of individuals described as autistic, so not all individuals will show the same profile of abilities and disabilities. In order to explore the possibilities of a movement disturbance for some individuals with autism, this discussion will shift the emphasis from a traditional interpretation of why communication, social interaction, learning and productive activity are so difficult to individuals with autism, which rests on notions of incompetence and lack of interest. Instead, we take the perspective that these difficulties may be the result of an underlying disturbance in expressive movement and its regulation.

Summary of Sources Proposing that Motor Disturbances are Associated with Autism and Other Neurological Syndromes

Motor Disturbance Phenomenon	Research Proposing an Association with Autism
Akinesia/Dyskinesia, Bradykinesia	Damasio & Maurer (1978); Maurer & Demasio (1982)
Tourette's Syndrom (stereotyped movement disorder)	Realmuto & Main (1982); Wing & Attwood (1987)
Apraxia/Dyspraxia	DeMyer et al., (1972); Jones & Prior (1985); Biklen (1990); Biklen (1992)
Catatonia (abnormalities in movement, volition, overall behavior and speech)	Wing & Attwood (1987); Realmuto & August (1991)
Emotional Dyskinesia	Maurer (1992)

II

Alternative Interpretations of Some Behaviors Commonly Observed in People Diagnosed with Autism

What is a movement disturbance like?

In the preceding pages we have described symptoms of movement disturbance and it is possible to examine each symptom separately. However, reports from individuals who have a movement disturbance make it clear that it is more than a simple collection of symptoms. The severity of a movement disturbance may be judged by the effect on the individual or partner in interaction. The degree of interference on interactions may be latent, distracting, disruptive, derailing or pervasive. Each episode in which movement disturbance is evident or experienced will vary depending on frequency, duration, intensity and composition of the disturbance. The constraints and forces on movement depend on balancing inhibition and activation in order to meet performance requirements during an interaction with a partner or alone.

For illustration, consider a simple controlled action, say reaching out to shake hands. As the arm rises and straightens activating and inhibiting muscles control speed and direction. If the inhibiting muscles were to exert more force than the activating muscles, instead of rising the arm would drop and bend. In the absence of an appropriate verbal or facial communication an observer might interpret the act as hostile withdrawal. On the other hand, if the activating forces are too great the arm may shoot out in a gesture all too easily interpreted as aggressive. Or if the movement was unimpaired but the reaction to slow the attempt might be missed, and the absense of timely response seen as lack of interest. In each case the person's attempt to interact would be misinterpreted.

In reality, various degrees of arousal, motivation and awareness are also brought to the balancing task. And a disturbance results when there is an inability to balance effectively the constraints and forces. Some individuals report that they are able to control certain symptoms for brief periods of time or in certain circumstances. Physical factors such as fatigue or illness may limit a person's ability to control symptoms. Emotional state and level

of intensity, whether positive or negative, may make the balance more difficult to achieve (Maurer, 1992, 1993). When friendliness can be conveyed only by awkward and childlike bobs, weaves and grunts, the impression gained might reasonably be of a primitive, infantile sensibility. In the following discussion of implications we will cover factors which influence the individual with movement disturbance, and suggest possibilities for interpretation of some of the unusual behaviors which are common in individuals with autism.

Automatic Responses

A person diagnosed with autism may become reliant on automatic or habitual movement patterns in order to move, communicate, and socialize. Automatic or habitual movements form the core of everyone's skill base and individuals with autism have shown ability to learn movements and language which are embedded in routines, or occur in response to specific cues. However, stimuli external to the individual may be more influential on behavior than any internal drive, desire or motivation. Involuntary and automatic responses to objects, locations, persons, words, or activities may compete and interfere with the individual's willed response. Other behavioral reactions may occur automatically in response to a person's inner thoughts and memories without clear and direct reference to the immediate environment. Some forms of verbal expression, (e.g. echolalia), may also be automatic and may be triggered by situations or events. This language may be related to a given context but will likely not adequately reflect the individual's intended meaning.

Automatic or habitual movements are movements which have become skills or second nature. One does not need to think and consider how to do an automatic movement. Some examples of automatic movements for many people include brushing teeth, operating a car, dancing with a familiar partner or reciting a poem learned in childhood. A characteristic of automatic behavior is that the context in which the skill was learned remains an important feature of the skill. Therefore a person may have difficulty brushing teeth if there is a need to use the nondominant hand. Dancing with a new partner can make one feel clumsy for a while, until the movements and cues become familiar. A difficulty generalizing from one environment or person to another is characteristic of automatic movement.

A number of the unique features of behavior and communication in autism have been assumed to be related to cognitive difficulties. When viewed within a movement framework it is possible to relate these features to a movement disturbance creating a dependence on automatic or habitual patterns. Features such as insistence on sameness, the use of rituals, strict adherence to routines, difficulty learning new language and motor skills and difficulty generalizing skills from one environment to another may be seen as reflecting a movement disturbance rather than a lack of

understanding or cognitive ability. Similarly, the use of immediate and delayed echolalia to communicate may reflect the individual's best attempt to use automatic speech in order to approximate the intended meaning. Certain language, actions and objects may be so closely associated with the automatic skill that their mere presence elicits a behavior, which may seem out of place. Just as a driver of a standard shift car may slam down a foot on the nonexistent clutch in the newly purchased automatic transmission car. A behavior that is not needed, but has been habitually learned, becomes difficult to inhibit. A person diagnosed with autism, for example, may find it impossible not to stand up and leave the room when he hears the word "Good-bye" spoken.

Many people with autism are known for their strict adherence to routines. This can take many forms including always performing a task in the same way, insisting that people sit in the same places each day, eating foods in a particular order and always taking the same route when walking for leisure. For some individuals the use of habitual or automatic movement extends to moving around within the house. If Bob wants to go to the kitchen from the living room he must first go into the washroom, flush the toilet and then enter the kitchen. If Rick leaves the living room via the center hallway door he will inevitably climb the stairs and enter his room. Once having entered his room he often changes his shirt and then is able to go downstairs and to the kitchen.

When caregivers figured out Rick's pattern of movements and saw some method in his rituals, life became somewhat easier. They no longer felt as though he were either lacking in understanding or avoiding tasks, so they were able to let him move in his own way and at his own pace. His automatic movements, although time consuming, were allowing him to independently move about the house without constant redirection and corrections from caregivers. As they, and we, understand more about movement disturbance perhaps he can be helped to short-cut some of these routines.

In addition to rituals involving body movement, individuals with autism frequently engage in verbal or social interaction rituals. Certain ways of interacting during specific situations may become repetitive. For example, always touching a person's forehead during greetings or asking the same questions repetitively. In his book, co-written with his mother, Sean Barron (Barron & Barron, 1992) describes his need to control interactions and people's reactions, creating a certain consistency and predictability. Temple Grandin (Grandin & Scariano, 1986) refers to the pleasure she felt when people gave the same answers to her repetitive questions.

The use of language and interaction rituals may represent individuals' attempts to internally call up certain emotional movements which are otherwise not readily available to them (Maurer, personal communication, Feb. 28, 1993). William, for example, is able to tell his mother he is upset,

but does not cry until he recites his "sad" poem. This is not unlike some techniques used in acting schools to help students capture the mood of a scene or character. Reliance on routines and rituals of interaction have often been reported to be a matter of choosing to interact in that specific way, however, several individuals have also reported that when they independently attempt to alter their rituals of interaction, they can not do so.

Stereotypic and Self Stimulatory Behaviors

Many people engage in seemingly meaningless, repetitive, or stereotypic movements. These behaviors may signal difficulty in moving on to new activities, (i.e. switching from one pattern of movement to another or between motor programs), and thus may occur automatically rather than being engaged in volitionally for purpose or pleasure. Points of transition may be especially problematic and likely to evoke such responses.

The repetitive rocking, humming, vocalizing, twirling and flapping of people with autism has been the focus of much research attention over the years. Often, researchers concluded that individuals engaged in these behaviors for pleasure and that the behaviors were self reinforcing. Some researchers have labeled these stereotypies as competing behaviors since they often occur at times when another person's agenda has been proposed. Teachers and caregivers sometimes assume that the individual is trying to avoid a particular task or activity. These explanations may hold true for some individuals at some times, however, there are alternative interpretations which bear examination.

It may be helpful to analyze transition points to demonstrate the number of specific adjustments that are needed in order to successfully move from one activity to another. The first adjustment needed is attentional, that is, redirecting the focus of attention from an activity which is in progress to the next activity. If one is to move from a solitary activity to one which involves another person, there is an additional change which includes establishing a relationship with the other person. Both of these changes involve voluntary movement, which may be challenging for people with movement disturbance. A synchrony of attention, thought, emotion and body orientation is required for even the most simple of transitions involving a partner. Many persons report that it is at these points of change that stereotypies are most likely to occur.

Another view of stereotypical behavior is given by two verbal people diagnosed with autism who are featured in an article that examined their experience of autism (Cesaroni & Garber, 1991). They reported that stereotypical behaviors occur during times when they are least aware or oriented to their surroundings. For one boy rocking and spinning occurred most frequently as a small child when his mother was not present. His attachment to his mother may have served to provide the synchrony of

attention, thought, emotion and activity required for engaging in play or interaction. The other young man noted that he did not consciously engage in repetitive movements, and that he did not do them for a reason. Instead he reported that they happened when he was not paying attention to his body, and that if he tried to think about how a particular movement like rocking feels, the movement would stop. This young man also reported that his mother was aware of these repetitive movements even before he was born. For both of these individuals, control over repetitive movements has been difficult and requires their constant vigilance.

Impulsive, Perseverative and Non-Responsive Behaviors

Some behaviors may occur impulsively despite an individual's desire to control them. At other times, the same individual may have difficulty initiating or terminating movements. These "inertial" behaviors, (i.e. not getting started or perseverating on previous movements) may be most evident when the individual is at rest, or is actively nearing completion of a task. The individual may have difficulty switching from one movement to the next and instead respond with continuation of the previous movement or posture. At other times, the individual may appear to "get stuck", adopt an unusual posture, or freeze in the middle of an activity, and be unable to continue. If a word or action from another person is required to accomplish transition the individual may be called "prompt dependent" for being unable to continue participation without the specific cue.

In considering impulsive behaviors, it is helpful to draw on the experiences of people with Tourette Syndrome. Situations, thoughts and things in the environment may create urges to perform certain actions, say certain things. One young man with Tourette described himself as seeing the possibilities for action and feeling compelled to follow through with them. When asked why he had touched and climbed on a stranger's car he replied, "It called to me."

The impulsive behaviors of some individuals with autism are easier to understand in the light these comparisons, especially when such impulses pull a person away from a preferred activity. Some individuals using facilitated communication have typed that there are often behaviors which they feel *compelled* to perform, but do not actually *wish* to perform. **"It's like my brain and my body disagree,"** typed one man with autism, referring to his impulsivity.

Educational programs and behavior management programs for individuals with autism have often focused on the development of compliance to instructions, utilizing tangible or social reinforcers to provide motivation for the individual. Often these programs have been effective in increasing people's abilities to respond more promptly when asked to do so. It may be that the success of these programs was in building a repertoire of automatic movements in response to instructions. The

difficulty in initiating actions and speech has been well established in the literature on autism. Often an individual knows perfectly well how to say something or how to perform a task, but cannot begin the task without cues from others.

This lack of ability to begin the task could be related to the akinesia or bradykinesia found in autism as well as Parkinsonism (Damasio & Maurer, 1978). Akinesia and bradykinesia are conditions which make the switching, starting, stopping or combining of movements difficult. Posturing, getting stuck, the lack of response or delay in responding seen in many individuals with autism could be related to these conditions. If this is the case, it may not be a lack of motivation or a lack of understanding which causes the individual's "non-compliance." Again the distinction between a behavior disorder and a neurological condition is highlighted. The behavior that is observed is the same (i.e. a lack of response to instructions); the assumptions about the source of the problem are different. This difference in assumptions affects the way we interact, our attitudes about the person and his motivations, and the amount and type of encouragement we might give to the individual. One young man using facilitated communication typed that he gets very discouraged by the emphasis on his negative behaviors and explained, **"I am sorry that I am like I am. If I knew how to be different...[I'd] find a way to stop these things."**

Individuals with Parkinsonism report that when they are "stuck" and find it difficult to initiate or stop a movement, a specific cue may be helpful (see Sacks, 1990). The variety of cues is endless and highly individual. In the same way that certain associations and cues can elicit unwanted automatic behavior, cues may also assist an individual in moving during difficult times. For individuals with autism, the reliance on cues from others has been described as "cue or prompt dependence" and has been assumed to be related to cognitive difficulties. This assumption is not made when people with Parkinsonism utilize cues from the environment or from other people. The need for cues in order to move, continue moving or complete an action may be viewed as characteristic of movement disturbance.

A careful analysis of the cues used during instruction and interaction with people with autism may yield valuable information. For example, cues which interrupt an ongoing task may become part of the task and need to be present in order for the individual to effectively utilize automatic movement. Cues which seem to help a person when he is "stuck" have been called accommodations (see Sacks, 1990) and can assist a person who is motivated but not able to initiate movement. The use of touch, music and certain rhythms are commonly reported to be effective accommodations. The use of touch in facilitated communication has been described as providing physical and emotional support so that an individual may express the ideas she has inside.

The assumption that cue dependency and non-responding are symptoms of

a behavior disorder rather than a movement disorder promotes the idea that individuals with autism lack understanding and motivation. The assumption in using accommodations is that certain cues assist a person to do what is intended but uncued is impossible. The Irish author and poet, Christopher Nolan, who is facilitated by his mother when he types with a unicorn, has the label of cerebral palsy. In his autobiography he describes why her accommodation works when electromechanical devices proposed by well-meaning engineers fail. Phil is the technologist, Joseph is the name Nolan uses, and Nora is Joseph's mother:

> **Used to describing his science in terms of being able to replace man's labors by the operation of one switch, Phil now found two strong hands able to do what a computer failed to accomplish. What have human hands got that a machine can't have, wondered the Research Fellow, and when Joseph rests his chin in Nora's cupped hands, what does that do for him, he mused. Joseph could have told him those two hands stream my head, as a pivot one moment, as a lift when I need to stretch forward, as a surefire suppressor of destructive lightning-fast electric charges, as a support when I'm just thinking. As hesitance masks most of my attempts to strike a letter, those hands wait and sensitively feeling my washed-up power, they hold my head until the spasm has wasted itself.**
>
> (Christopher Nolan, 1987)

Unpredictable Behaviors

The unpredictable and often dangerous behaviors of individuals with autism have long puzzled parents and practitioners. Our usual observational tools, behavior analyses and pharmaceutical interventions are sometimes not helpful in understanding behaviors that seem to have no clear cause or antecedent. Such behaviors of excess were described more than one hundred years ago (Kahlbaum 1874/1973) in relation to individuals who had developed catatonia following encephalitis. Kahlbaum's patients typically went through cycles of random bursts of self-injury, aggression or bouncing off walls. When asked about their behaviors during more lucid times they were often unaware that the behaviors had occurred. It may be helpful to presume that many behaviors which do not have an observable cause may be the result of internal neurological events, emotions, perceptions or thoughts to which an observer does not have access.

Significant bursts in the level and intensity of actions that are random and transient, (e.g. self-injury, aggression, running), may be triggered by internal neurological events, and perhaps related to partial seizure activity. The individual may have difficulty controlling and suppressing these behaviors independently. Some behaviors may become environmentally conditioned over time. Other external stimuli that typically excite specific sensory pathways, (e.g. noises, lights, textures), may overflow and excite

more than one sensory pathway resulting in apparent, severe over-reactions, (e.g. tantrums), that are difficult for the individual to inhibit.

Often people with autism report unusual sensitivities to sensory stimuli such as sounds, smells, lights or tactile stimulation, and facilitated communication has revealed that some experience a condition known as "synesthesia," or a crossing over of sensation from light to sound to touch smell and taste. Synesthesia is regarded as a mostly positive attribute by unimpaired persons who possess it. Cesaroni and Garber (1991) report some unusual sensitivities and mixing of sensory input for the two verbal young men diagnosed with autism they interviewed. Touch in a certain area of the face produces a "auditory" sensation for one young man. He also reported some confusion in identifying the sensory source when, for example, he sees a color along with hearing a sound. Other sounds trigger a disorientation which he finds difficult to explain. A nonverbal man diagnosed with autism spelled out, **"I see things all different I see sounds and hear color only some people do that I think it is wonderful."**

Although individuals with autism have traditionally been described as lacking in feeling for others, some individuals report the opposite. Jim (Cesaroni & Garber, 1991) told the researchers that he sometimes "spends enormous energy connecting with another person" while others have reported difficulty because of an unwanted "catching" of other people's emotions. Certainly individuals with autism are not the only ones to find that emotions are contagious, as any classroom teacher can attest. However, most adults are able to routinely move to a state of emotional control. Martin reported through a facilitated communication that he often feels forced or compelled to "echo" the emotions of another and may get "stuck" in that adopted emotion. This could be seen as parallel to the forced physical mimicry or "hypermimesis" experienced by some individuals with Tourette and autism. The forced imitation of a person's emotional state lends new meaning to the idea of "living up to someone's expectations." Is it possible that a teacher or caregiver's fear of some dangerous behavior becomes the cause of fear in the individual with autism, which leads to the dangerous behavior? When asked to describe herself, Sheila, using facilitated communication, typed, **"I am like a song. You can sing with me or you can turn me off."** Consideration of the effects of relationship may be useful in exploring beyond the directly observable events leading to unpredictable behaviors.

In summary, individuals with autism may display movements that are not desired by them but are out of their control. They may find that their bodies betray them in carrying out volitional actions. Communication may be difficult, not because they fail to understand, but because they are unable to express their meaning in an accurate and precise way. Some desired responses may get sidelined by more powerful distractions posed by the environment that the individual to wants ignore and quit but cannot inhibit. Other responses may be accommodations in the sense that they are active

attempts of the individual to comply with situational demands to perform specific actions. A sad misunderstanding of such an accommodation that was discovered and corrected with the help of facilitated communication involved a young man who was punished for tearing up his bedding until he communicated that tearing his mattress helped him stay away from tearing at his face. Such responses may not be as meaningless or inappropriate as they appear to others. Clearly, erroneous judgments concerning an individual's competencies may result when we base such determinations only on what we see. It is especially tragic when individuals are punished for behaviors they can not stop.

III

Some Clinical Applications of Movement Disturbance Theory

In our recent clinical experience we have found this different perspective on behavior in autism to be seemingly valid for a number of individuals and worthy of further investigation. Although preliminary, the following are samples of approaches that we have explored so far. Many others will likely be developed as we gain experience.

Our observations and analyses of a person's behaviors or movements are made within the context of a possible disturbance of expressive movement. For example, considerations of difficulties initiating or terminating a movement are likely to replace previous accounts of "non-compliance" or "engaged in self-stimulatory behavior."

It has always been true that the most useful definition of behavior has focused on describing what we are able to see (e.g. Greg rocks his body from side to side after an instruction is given). However, in practice we are often tempted to take short cuts in our descriptions (e.g. Greg engages in "self-stim" after an instruction is given). The use of definitions that label rather than describe behaviors often leads to assumptions about the person's motivation for engaging in the behavior. That is, the label of self-stimulation causes us to assume that the individual finds the action self-reinforcing or pleasurable. Self-stimulation is assumed to be the individual's way of saying that she would rather not pay attention to us; she would rather seek pleasure in her own repetitive activity. This assumption may be true for some people, some of the time, and has been useful in analysing tasks to make them more interesting to such people. It now seems appropriate to broaden our assumptions. These behaviors may be internally triggered at times, or even be necessary accomodations to complete another movement.

Recently we have been giving consideration to the difficulties people may experience when attempting to **start** new movements, tasks or interactions, **combine** movements, **regulate** the speed or intensity of movements, or to **stop** actions that are in progress. Our analyses of the behaviors which we see during the "transition times" (e.g. between activities, or between steps

in a task) has taken on a new focus. In addition to observing responses to instructions, we are spending more observation time noting when people are able to stop, start and regulate actions on their own. We have observed that many people have discovered "accommodations" such as external or self-induced cues which they use routinely to regulate their actions.

Clinical Considerations of Movement Disturbance

The underlying disturbance is marked by difficulties in:

Starting	——>	Postures
Executing	and	
	——>	Actions
Continuing	impedes	
	——>	Speech
Stopping	achieving	
	——>	Thoughts
Combining	these	
	——>	Perceptions
Switching	goals	
	——>	Emotions

Figure 1

Our understanding of the movement aspects of relationship has heightened our awareness of the rhythm, emotion and choreography of our interaction with individuals with autism. As speech language pathologists we have always been interested in the construction and expression of meaning between partners. When we turned our attention to the difficulties which may be encountered in organizing body movements to express meaning we began to take a closer look at the synchrony of movement required to establish and maintain a relationship. Our analysis has been enriched by the recognition of the rhythm, shape and patterns of movement between people which may signal certain emotional states.

Recently a staff person noted that eight year old Jeremy has patterns of behavior/movement which are well-established and seem to be specific to the person he is relating to. With Mom, Jeremy drapes his body on hers, cuddling and snuggling. He sits very upright and attentive during group instruction when his teacher stands at the front of the class. When Jeremy sees his teaching assistant he seems to lose some control of his body and becomes floppy, sliding off his chair. The teaching assistant finds she must always use physical prompting to assist Jeremy to participate.

Using our standard model for analysis, we may have concluded that certain partners reinforced inappropriate behaviors, while others did not. However, despite the best efforts of each of these partners, the "signature" movement patterns persist. We wonder if the perceptions, expectations, and

emotional synchrony of these relationships have shaped the quality and nature of Jeremy's movements during interactions with each of the partners. Does Jeremy experience powerful urges to relate in certain ways which have become automatic responses to particular feelings or people? Our understanding of these aspects of relationship is in its infancy. We do not know whether these insights will provide us with new strategies for assisting children like Jeremy.

We have found it useful to draw upon the experience of persons with movement disorders in an attempt to understand the nature of accommodations. Accommodations are the individually determined acts, images, sounds, etc. which assist a person who is "stuck" to move on. Specific gestural prompts; changes in stimuli; the influence of another person's movement; touch and physical assistance; visualization of participation in the next event; and music have all been reported to assist individuals in accommodation.

Examples of Accomodations Related to Communication

Staying near/Developing relationships

- Franco's mother reports that a hand touching his back helps Franco pay attention during conversation.

Using speech

- Reciting poems that match his feelings helps Chris express emotion that otherwise would remain hidden.

Using symbols

- Typing or writing your questions and giving them to her to read helps Donna respond to them.

Table 6

The example of Hassam may serve to illustrate how we applied a theory of accommodations. When approached by staff who stood in front of him, stationary, clearly stating their instruction (e.g. "Hassam, stand up.") Hassam was rarely able to do so without additional cues from staff such as physical assistance, or verbal or visual references for reinforcers, etc. This condition had lead us to believe that Hassam lacked motivation to participate. Observation of Hassam from a movement perspective meant that we watched him during all sorts of solitary activities and social interactions to note his accommodations, that is, "what seems to help Hassam to move." It was noted consistently that he was able to cease rocking back and forth on the couch and actually initiated standing up and moving across the room when other people also got up from a sitting position. A simple enough observation; nothing earth shattering in that.

Of course, our approach to Hassam changed immediately. First, we assumed that he likes to participate in most activities because he wants to

learn more and be a part of what is happening. Second, we assumed that Hassam is like the staff who work in his home in that a brief period of chit chat and social exchange is often necessary for any cooperative endeavor. We sit beside him, talk about what is coming up, how things went yesterday, how pleased everyone is that the activity goes better each day, how we have confidence in his abilities, and so on. When we feel that we are *both* ready we stand up and offer a hand to Hassam without saying a word. This process takes about the same amount of time needed previously to move from one level of prompts to another—about one minute.

Initially the new procedure worked only marginally better than the old ones. The important benefits of the accommodation came slowly in terms of Hassam's ability to respond when preparing for an activity. The changes in staff attitudes and observation skills came more quickly. Staff were able to generalize the idea that Hassam moved more easily with the rhythm of another person. They began assisting him to learn to walk rather than letting him rush ahead when walking for leisure. More tasks were set up to include working in parallel with Hassam rather than watching and prompting as he worked alone. More important, staff no longer felt as though they were forcing Hassam to participate in activities he hated. They were able to interpret his responses in some cases as difficulty initiating, controlling the rate, or stopping a movement. Occasionally, as with the rest of us, Hassam did not wish to comply or to participate.

Our instructional programs attempt to build on the individual's relative competency in acquiring functional, automatic movements in specific routines or situations. The teaching of alternatives or new automatic/habitual responses to stimuli which have elicited self-injury or aggression in the past, although hardly a new concept, fits well into our new approach. As noted earlier, automatic behaviors are a necessary component of our skill base. However, it is sometimes the case that an individual develops an automatic response to various external or internal events which is dangerous, destructive, or interferes with his ability to learn new skills. The work of practitioners who attempt to change behavior through non-aversive strategies continues to be helpful when viewing behavior within a movement framework. LaVigna and Donnellan (1986) detail specific aspects of the development of alternatives to behaviors which are problematic and offer suggestions to avoid "prompt dependency" (see Donnellan, LaVigna, Negri–Shoultz & Fassbender, 1988, LaVigna and Donnellan, 1986, Chapter V).

Our observations and analyses of an individual's communicative acts reflect the possibility that speech, sign language, gesture, and other expressive movements may be most accurately produced (though not necessarily what the individual wishes) when part of automatic or habitual routine. Repetitive speech, sign, etc. may be indicative of "getting stuck" and spontaneous, volitional communication may be seriously curtailed by a general expressive movement disorder. The provision of physical

assistance and emotional support to access augmentative communication systems, as in facilitated communication, seems worthy of consideration and trial.

We continue to assist people in learning to use their competencies in automatic communication (e.g. echolalia) to express as much meaning as possible. Our interpretations of the possible meanings intended by a speaker have become less literal, knowing that automatic or habitual communicative acts may only partially reflect a person's meaning. On the other hand, we no longer accept that behaviors that are automatic are also meaningless. For example, a young man who for years had perseveratively played songs from *The Sound of Music* regularly chose *"How Do You Solve a Problem Like Maria?"* after conflicts with his mother, whose name is Mary! Through facilitated communication he has confirmed that his selection was not accidental.

The introduction of facilitated communication to North America has caused us to consider the reasons why some people may be able to express a wider variety of communicative intentions when a facilitator provides physical and emotional support. Within the context of movement disturbance some of the more puzzling aspects of this phenomenon become open to an alternative interpretation. First, the idea that is possible for an individual to have competencies which are not observable has been demonstrated in the literature on post-encephalitic Parkinsonism and catatonia (see Sacks, 1990; Kahlbaum, 1874/1973). Second, the literature on accommodations used by and with individuals with Parkinsonism has clearly illustrated that touch can serve as a powerful stimulus for movement which was not possible without it (see Sacks, 1990). When viewed as an accommodation, facilitated communication as it is currently described become one possibility among many potential accommodations which may assist people to communicate.

Most dramatically, the approach allows us to interact very differently with individuals with autism. The approach credits the individual with competencies that may not be directly apparent through observing performance alone. This has been a most positive turn of events for all involved.

Our use of language and our interaction style now assumes that a person may often understand but be unable to demonstrate that understanding. This is a basic assumption when working with individuals with stroke, traumatic brain injury and other impairments. When we applied it to people diagnosed with autism and other developmental disabilities we were amazed at the positive effect that it had on our relationships with them. That is not to say that they always understand all that is said to them (who does?); but the confidence which is expressed by this small courtesy assists immeasurably in building honest and trusting relationships.

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Anne M. Donnellan, PhD, series editor, is a Professor in the School of Education at the University of Wisconsin–Madison. A long time member of the Professional Advisory Panel of the Autism Society of America, she is known internationally for her numerous books and articles, and her training, research and advocacy work on behalf of children and adults with significant communication and behavior disorders.

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***"Movin' On"* Beyond Facilitated Communication** is a series of short books written by clinicians, parents, administrators and advocates, with the cooperation of facilitating communicators, that introduce readers to the changes created by Facilitated Communication. It is the editors' goal to provide up to date information, experience and opinion in a form accessible to everyone interested in the the welfare of peope labeled developmentally disabled. Many of the topics presented in the series are still being researched by the scientific and academic communities. Every attempt will be made to keep the information current, as in a rapidly developing field such as this we believe that concerned need to share their experience even as we await the research results. The solution to complex situations we face will come from dialogue among practitioners, researchers and consumers. We hope this series contributes to that dialogue.

We have chosen authors who have broad experience, take responsible positions and demonstrate good values. We do not always agree with their comments but believe they have important perspectives to share. This monograph is an excellent example. David Hill and Martha Leary are truly gifted speech pathologists who combine highly developed clinical skills, searching intelligence and extraordinary energy. The advent of facilitated communication prompted them to comb the professional literature for information that would provide a foundation on which to place this communication breakthrough and a theoretical structure upon which further advances could be built. We believe they have succeeded brilliantly, and that this monograph provides a perspective that clinicians and researchers will follow for many years.

We encourage you, our readers, to send us comments on the works in the ***"Movin' On"*** series, on your own experience and on other topics you think we should pursue.

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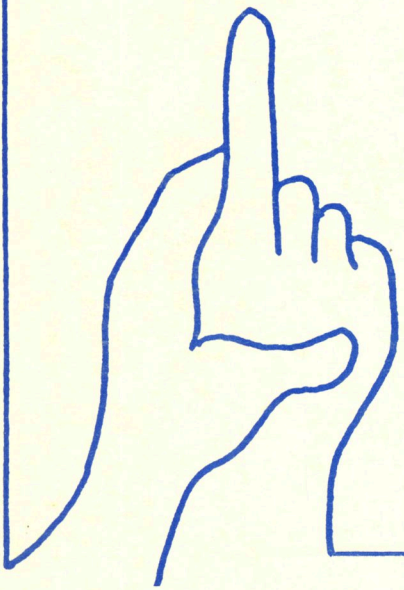

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